

OCALI | Podcast – Episode 21

Interview with Sheila Graschinsky

[RADIO CHANGING STATIONS] [THEME MUSIC]

SIMON BUEHRER: Welcome to Inspiring Change from OCALI, our forum of stories and connections from our ongoing work of inspiring change and promoting access for people with disabilities. I'm Simon Buehrer.

SHEILA GRASCHINSKY: When I was 12, I didn't know about disability. I didn't know how to play with a boy, like my son. Ian was born in 2007 and due to a lack of oxygen, Ian has a motor disability.

Not only that we had to work with inclusion, not only that we had to manage this anger, but also to be active in this way, to get to society, and to make society get involved. And we decided as a family to live, like turning anger, into action.

SIMON BUEHRER: What does inclusion mean, and how does it happen?

Well, like with almost anything, sometimes it helps if you start with a story. Stories are foundational. They're fundamental to our existence as human beings. Think about the best or most memorable moments from your life. I guarantee there's a story there and probably one you and your family and friends enjoy retelling and reliving.

I've been saying for years, that formal education and even office drudgery, would improve 1,000 fold if you could somehow turn every task, assignment, or problem into an engaging and compelling narrative.

I know that's not practical, but the point is that good stories are transformational. They can reach us at our very essence, at our core. They can impact and change who we are, what we know, what we believe. They're the social stitching that helps us connect, understand, and grow with each other. And given all the divides that divide us, perhaps building and sharing stories are some of the most important things that we can do for each other and for our society as a whole.

OK. So back to our original questions-- what does inclusion mean, and how does it happen? For Sheila Graschinsky, the answer to both of these questions came through a literal story called The Gift.

SHEILA GRASCHINSKY: When I wrote the book, I was able to give it to many families and children. And many parents helped our foundation buying the books, and they received, during that year, many, many pictures and messages of parents telling me that their sons had chosen that story to share at school when they have like-- in Argentina, there is something very

common, they ask for children to share their favorite story, their favorite book, and they were all choosing this book.

And I am sure it's because they feel empowered. They feel they have a new knowledge and that they can help with that, and they want to share it.

SIMON BUEHRER: OK. Let's back up just a little bit.

SHEILA GRASCHINSKY: So that was something very inspiring.

SIMON BUEHRER: Sheila Graschinsky. Sheila, did I pronounce that correctly?

SHEILA GRASCHINSKY: It's OK. Graschinsky.

SIMON BUEHRER: Graschinsky.

SHEILA GRASCHINSKY: You are doing very well.

SIMON BUEHRER: OK. Let me try it. Graschinsky.

SHEILA GRASCHINSKY: Yeah.

SIMON BUEHRER: OK. Better... She's the founder and President of Fundación IAN, an organization in Buenos Aires focused on promoting a diverse and inclusive society. Sheila is the mother of four boys, the youngest of which, Ian, was the inspiration for the book, *The Gift*, as well as the foundation that bears his name.

And there's also a short animated film, called Ian. You can watch it right now, for free, on YouTube. Search for Ian by CG Bros. That's CG b-r-o-s. If you've never seen it, go watch it. It'll be the best 10 minutes of your day.

We sat down with Sheila to talk about her and Ian's journey and their ongoing efforts towards building inclusion one reader, one viewer at a time.

SHEILA GRASCHINSKY: Ian was born in 2007 and due to a lack of oxygen, Ian has a motor disability, which impairs him to move and talk and coordinate some movements.

Ian is now 11 years old. It's been a long path. Being a mother of a child with a disability has a lot of things to learn about. As I say, I had to learn about medicine, a lot about laws, and when talking about Ian and all his treatment, I also say that it's as if I run a small business at home. He has more than seven therapies that I have to coordinate and all the treatments and so--

SIMON BUEHRER: That's a lot.

SHEILA GRASCHINSKY: --it's a tough work.

SIMON BUEHRER: It's a lot. So tell us a little bit about-- the film was based, in large part, on experiences that both of you had, you as Ian's mother and then, obviously, himself going through schooling. So I'm sorry, he was born in 2007--

SHEILA GRASCHINSKY: Yes.

SIMON BUEHRER: --correct? OK. So talk a little bit about those experiences, and how they led to not only the film but the book as well.

SHEILA GRASCHINSKY: The short film, Ian, a moving story, which is based on a true story. You can find it in the internet. It's a short film. It's a 9-minute short film, animated short film.

SIMON BUEHRER: No excuses. Everybody can watch it.

SHEILA GRASCHINSKY: It has no language, only music and emotions. So it's a wonderful piece to talk about inclusion. And yes, as you were saying, it's all based on a true story. Being a mother to a child with disabilities, it puts you in front of many barriers and obstacles you have to go through.

And the short film was inspired on a true story going to a rehabilitation center where my son would practice how to use a computer he manages with his eyes. With his computer, Ian can talk and can communicate and play. And from my foundation, we teach therapists how to use the computer. In Latin America, this was not known some years ago. I'm talking about, like, six years ago. So we brought this technology to Argentina.

SIMON BUEHRER: He was a pioneer, like one of the first?

SHEILA GRASCHINSKY: Yes, he was the first children in our country using this communication system. By looking at the computer, he can activate different messages, and he can also activate letters so then he can write and communicate his idea.

So I was taking him to a rehabilitation center where they will teach him how to use the symbolistics in order to talk. And in front that center, there's a school, a primary school, and the first time I took Ian, I could hear some children behind a window laughing at Ian's disability. Of course Ian's, and many other children, were getting to the treatment center. So well, I just started walking faster in order for him not to listen to me.

The second day, I went to the treatment center and saw the same situation. I started to sing at Ian and try once more not to be disturbed by the situation. And the third time, my son started to cry. And maybe I was not on my best day so I got mad at it.

And after leaving Ian at his therapist, I crossed the street and knocked the door into the school. I was very angry. I wanted to speak with principals and in my head, I remember I had many ideas and insults and not happy things, thinking. And I waited for the principals to come, like five minutes, which, I think, that were transforming for me in a way.

I was in school, waiting for the principals, surrounded by many children, some of them playing with balls and in front, the treatment centers where I could see children waiting in ambulances, some of them needing oxygen to breathe. No noise, just the noise of the strollers.

And I asked myself, what was the difference those boys at school with 11 or 12 years had from what I knew about disability when I was 11 or 12 years? And the truth is that the kids had gone through, and there were no difference. When I was 12, I didn't know about disability. I didn't know how to play with a boy like my son.

So I remember getting out of the school, getting to the street and crying for 45 minutes. That was the period my son was in his therapist, in his speech therapist. And then, well, I knocked the door at the rehabilitation centers, I got to Ian and told him that I've been at the school and that I realized that getting angry at the children who were laughing about his disability, would be no answer to the situation, would be no solution.

So I said, what do you think if we write a book to show those children that you are also a child who has rights, who wants to play, who can do many things if they help you. So we did that. We wrote a book that is called The Gift.

And during a whole year, I took that book, like two or three examples, when I would be with my son and if any situation, any children would laugh at him or would leave him apart, instead of getting angry, we would give him a book. And during a whole year, we could see how things changed, and the child who would bully at him, after reading the book, would get closer, say hello, ask him if he was OK, if he wanted to play.

So that was very inspiring for us. And it showed us a path not only that we had to work with inclusion, not only that we had to manage this anger, but also to be active in this way to get to society and to make society get involved. And we decided, as a family, to live like turning anger into action.

When I wrote the book, I was able to give it to many families and children. And many parents helped our foundation buying the books, and they received, during that year, many, many pictures and messages of parents telling me that their sons had chosen that story to share at school when they have like-- in Argentina, there is something very common, they ask for children to share their favorite story, their favorite book, and they were all choosing this book.

And I am sure it's because they feel empowered. They feel they have a new knowledge and that they can help with that, and they want to share it. So that was something very inspiring.

And especially, when I saw that the same children that would laugh at Ian or that would not play with him, after reading the book, they would get closer to my son, ask him questions, telling other children about Ian's abilities. So that's why, after a year, I started thinking to get to every home around the world. And today, with children that they are so active with the technology and to processing the information in this format, you were saying, in this way, I thought about creating a short film.

And that's how Ian, a moving story was born. And it's based on a true story. It's the story behind the book. It's the story that made us write the book. It's the real story and my son participated a lot in creating the short film.

I will always remember that the producers, the short film producers, asked me if they could have some points of view of Ian. How he felt that moment, what he would like the message to be. And Ian said that he felt he would love to being able to fly so he could go and help the children that were bullying him and tell them that it's not that he didn't want to play, it was that he couldn't, but if they help him, he would be able.

We are all made of little pieces of our own experience, of our own lives' experiences. And when inclusion occurs, when inclusion happens, these pieces mix up together, and you can get some other pieces of a classmate, and you grow as a person, and society grows when including.

I always say that the short film opens doors to talk about inclusion, and it's a beginning point. It gets to emotions. So it provokes children and teachers to go and reach the information through emotions, which is quite different studying something or having to read about disabilities. You touch emotion, and you provoke the desire to know more.

Children without any kind of disability, raising up the hand and saying, many times I feel like Ian. So imagine.

SIMON BUEHRER: Well, it's a universal story. I mean, I don't think it's limited to--

SHEILA GRASCHINSKY: To disabilities.

SIMON BUEHRER: Exactly. Exactly. I mean, we talk about community, I mean, that's what we mean, right? Community is all of us, and we see ourselves in Ian, and Ian is part of who we are.

I did want to ask you, Sheila, the decision not to have any language or speaking parts at all, I believe, was deliberate. Can you talk a little bit about why the film was--

SHEILA GRASCHINSKY: OK. I have another story for that.

SIMON BUEHRER: Great.

SHEILA GRASCHINSKY: I didn't know it didn't have any language until one day I went to the studio, to Mundoloco, where the film was created. So one day I went there. They were going to show me some advances, and some new ideas.

And I met the director, I told him, have you chosen the voice? Ian's mother's voice? And he told me, there's no voices, there's no language. And I said, no way. How are you going to transmit and show what the mother thought? And her ideas? And how worried she was? And the love she had when he left his son? And he said, there are no words needed.

But, you know, it was a great decision because now we are getting to many people from different countries. I would say, I want this film to touch hearts. Not only children hearts, but I want to touch their parents' heart, directors' of companies heart, I want to get to all places. All of us, as part of a society, should take into account all of our inclusion.

SIMON BUEHRER: What I love is that it started with a story. It was a story that made it possible. The books that you were handing out and now this film, which has a universal appeal, it just speaks to the emotive, the power that a story can have in lives.

SHEILA GRASCHINSKY: Yes, and how it--

SIMON BUEHRER: How it can prompt action.

SHEILA GRASCHINSKY: --made it possible to get together many people who started dreaming with us. It's been a lot of work and a lot of commitment and a whole industry that got together to work for inclusion. So that's a huge example for society, in general.

SIMON BUEHRER: I love that you said that Ian was involved in the film, and I just wondered if you could talk a little bit about what having his active involvement and his sort of guidance and perspective.

SHEILA GRASCHINSKY: Yes, he--

SIMON BUEHRER: I think that's an important part of it.

SHEILA GRASCHINSKY: --he participated during all the process. We'd been working on the film for one year. As I told you, more than 50 persons, artists working on it after their working time.

And yes, Ian took part from the very beginning when we asked him some questions. What he wanted the children to transmit, how he wanted to tell the story. He said he wanted to fly and hug, so that's how we decided how we were going to treat and made us decide to construct the characters from small pieces. Well, he also went and saw how it was getting to the final product and the music and he was an active part.

Of all the things, including people, we all win. Making universal designs, we all win. It's not for that person with disability. It's for society as a whole. And I'm very convinced about that.

And being a mother to Ian and my three other children, and they go to an inclusive school, and I can say that for Ian, the school he goes, it's great. And of course, he had a lot of nice experiences.

But the best is for Ian's classmates. They've learned something that changed their lives. They've been able to have a powerful story all days inside their classes. And those children are going to be very different.

SIMON BUEHRER: That was a conversation with Sheila Grschinsky, president and CEO of Fundación IAN, an organization in Buenos Aires, Argentina, focused on promoting a diverse and inclusive society. You can learn more about their work and ongoing efforts at [fundacionian, all one word, dot com](http://fundacionian.com). And that's f-u-n-d-a-c-i-o-n-i-a-n dot com.

As you can probably guess, the native site is en Español, but most web browsers have free translation tools or plugins that will translate it into English. And again, you can watch Ian, the short animated film on YouTube. Search for Ian, i-a-n, by CG Bros. That's c-g b-r-o-s.

Thanks again to Sheila for sharing her and Ian's story with us and for their continued and tireless efforts to promote a diverse and inclusive society.

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Also, be sure to check out our sister podcast, From My Perspective, hosted by my colleague and friend, Jen Bavry, from the Family and Community Outreach Center here at OCALI.

Thanks again for listening to Inspiring Change, because the need for change is everywhere and inspiration can come from anywhere.

I'm Simon Buehrer. See you soon.

[MUSIC PLAYING]